

**NOTHING ABOUT US  
WITHOUT US!**

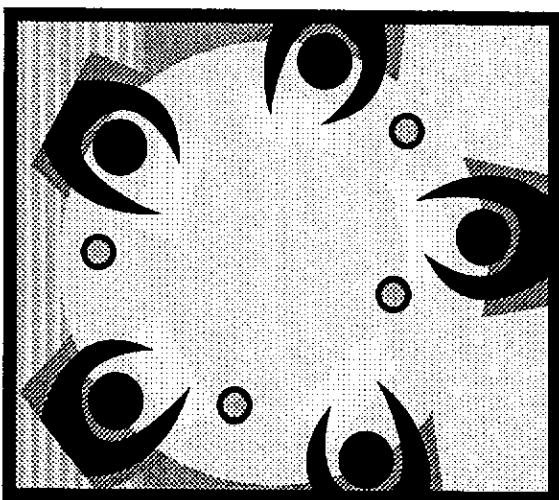
Aurora Consumer  
Conference

September 23, 2003

EI

## Promoting Meaningful Consumer and Family Member Involvement

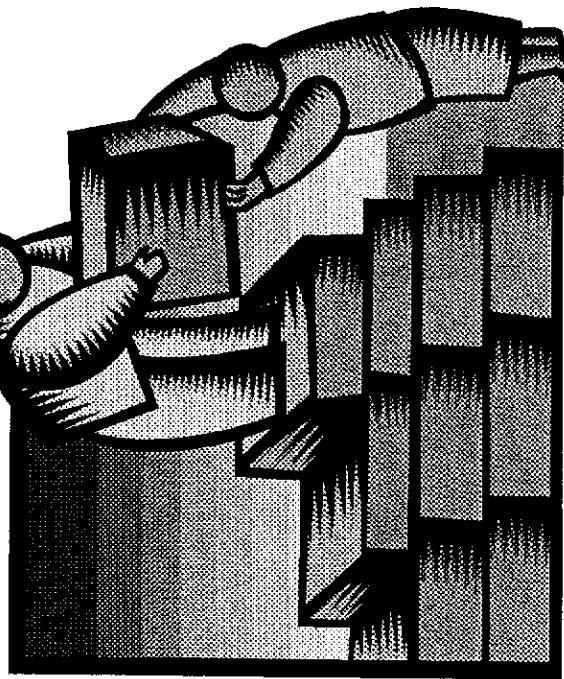
Each represents their own circumstance and point of view: Many consumers are family members and many family members are consumers; however, where you stand depends on where you sit, as they say....



- Classic example of perspectives:

- A consumer may say to family members, “You may not choose for us what we would choose for ourselves.”
- A family member may say to a consumer “We are acting in your best interests. We are only trying to help.”

- Consumers might seek out services rather than being forced into them because the services and supports would be designed by consumers and be what they voluntarily want and need



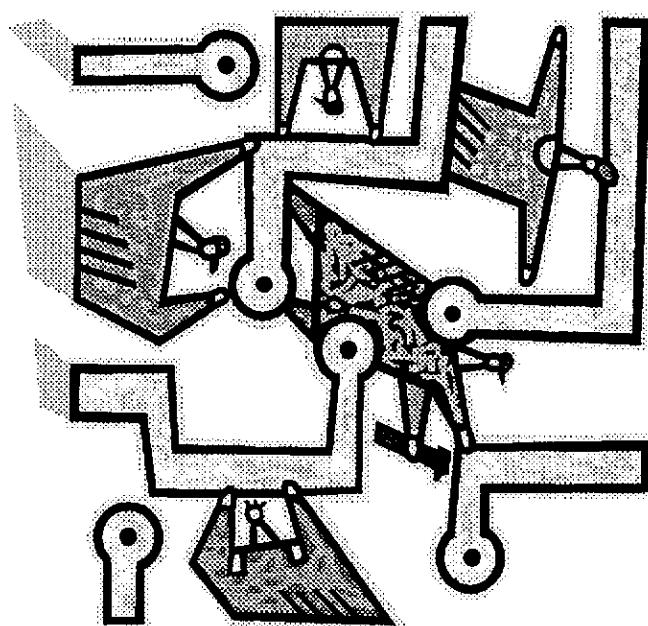
“A truly mature mental health system would be one in which it is taken for granted that consumer/survivors are included and actively involved at all levels of the mental health services delivery system, including the uppermost levels of management and policy making”.

(McCabe & Unzicker 1995)

## **Why Involve Consumers and Family Members?**

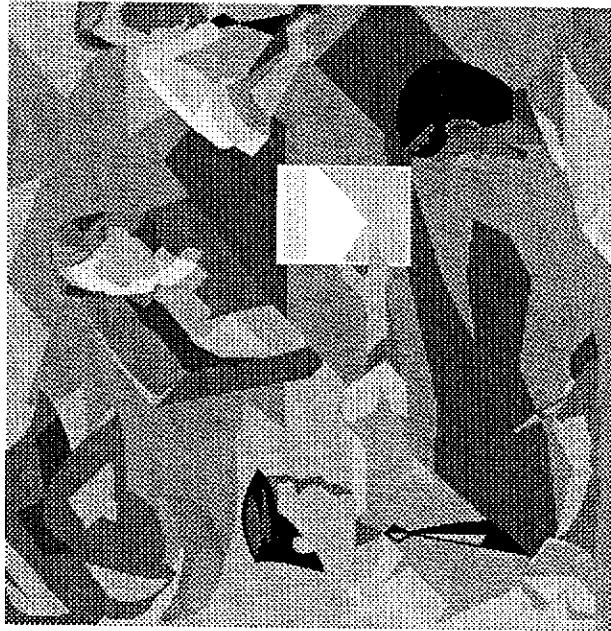
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- Experiential knowledge brings unique perspectives
- Multiple perspectives are key to good decision-making
- All people deserve to participate in decisions that affect their lives
- No one else can speak for us—we need to speak for ourselves



## **What is “Meaningful Involvement”?**

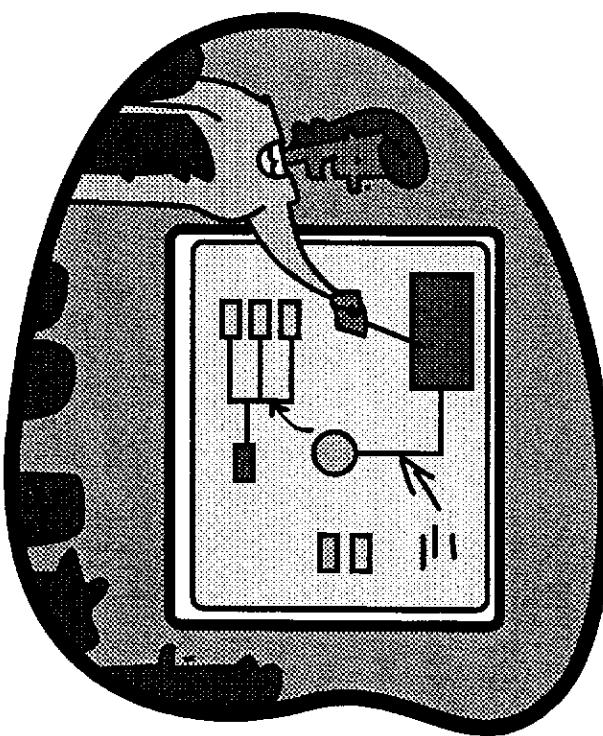
- Beyond tokenism:  
sufficient numbers to  
have real influence
- Beyond review &  
comment: Involved in  
framing the issues and  
setting the Agenda
- Beyond advice:  
participating in  
governance and policy-  
making
- Beyond sign-off: directing  
one’s own recovery



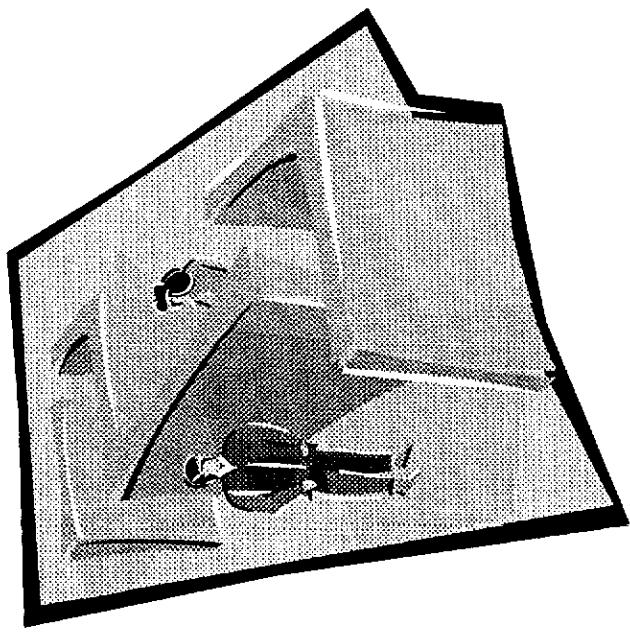
## **Involvement in All Areas and at All Levels**

National, state, regional,  
and local provider levels:

- Planning, policy-making
- Legislation, governance
- Program design, implementation, evaluation, and monitoring
- Education and training
- Service provision



## **Barriers to Consumer and Family Member Involvement**



## **Procedural Barriers**

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Can be easily remedied:

- Inconvenient meetings times
- Lack of transportation
- Insufficient numbers of consumers and family members
- Lack of adequate notice of meetings
- Insufficient information sharing

## **Dealing with Procedural Barriers**

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### **Problem:**

- Consumer/survivors work, school or program conflicts with daytime meetings.
- Consumer/survivors don't have own cars, can't afford cabs
- Medication side-effects make it hard to concentrate or sit still for long periods

### **Solution:**

- Schedule evening, weekends, meeting meet at program offices
- Carpool, reimburse for cabs and public transportation
- Adequate number of breaks, respect people's need to pace or leave and return

## **Structural Barriers**

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- Require more intensive interventions
- Lack of orientation for consumers and family members
- Closed bureaucratic processes
- Agenda framed from provider perspective
- Lack of skills training, support & technical assistance

## **Dealing with Structural Barriers**

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Structural barriers are inherent in the way business is conducted. While obvious to outsiders, often invisible to insiders. Remedies require intensive work, perhaps reorganization.

## **Dealing with Structural Barriers**

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### **Problem:**

- Closed bureaucratic process, not accessible to consumer and family members
- Consumer and family members may lack meeting skills, may not understand system

### **Solution:**

- Reform and open up process; orientation for consumer and family members

- Peer education, technical assistance

## **Attitudinal Barriers**

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- Root of the other barriers
- Paternalism
- Belief that consumers and family members cannot understand complicated information
- Professionals threatened by consumer and family member's challenges to status quo.

## **Dealing with Attitudinal Barriers**

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Hardest barriers to address, but most crucial. Based on unexamined prejudices, lack of information, fear, paternalism, inherent power imbalance, misplaced self-interest.

## **Dealing with Attitudinal Barriers**

### **Problem:**

- Professionals ignorant of consumer and family member perspective

### **Solution:**

- Education of consumer and family member issues and perspectives by consumer and family members
- Structured dialogue to overcome power differential
- Leadership values consumer and family member's input, model for staff
- Professionals ignore consumer and family member's input

## **NEW APPROACHES**

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- Managing Conflict Cooperatively: “Making a Commitment to Nonviolence and Recovery in Mental Health Treatment Settings”:
- Describes how conflict management fits in the mental health field and discusses the roots of trauma.
- Gives applications of conflict management and alternative dispute resolution in community mental health settings, emergency rooms, state hospitals admissions, inpatient wards and hospital treatment and discharge planning.

- Shows how conflict management can change organizational culture, with seclusion and restraint as a specific application.
- Proposes future directions and recommendations to the National Association of State Mental Health Program Directors (NASMHPD)
- [www.fmhi.usf.edu/mediation](http://www.fmhi.usf.edu/mediation)